

**Day-to-day living with severe chronic obstructive pulmonary disease: Towards a family-based approach to the illness impacts**

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## Abstract

**Objective:** This study explores the perspectives of both patients and family members regarding the impact of chronic obstructive pulmonary disease (COPD) in their family life.

**Design:** An exploratory qualitative study was conducted with patients and their family members in the chronic phase of COPD. Individual interviews were performed to explore participants' perspectives and submitted to thematic analysis.

**Results:** Six major themes emerged from patients' perspective: (1) impact of COPD symptoms on personal and family daily life; (2) (over)protective family support; (3) difficulties in couple communication; (4) sense of identity loss; (5) fear of COPD progression; and (6) coping resources. Five main themes emerged from the family members' perspective: (1) restrictions in family's social life; (2) emotional distress related to COPD exacerbations; (3) tension in couple relationship; (4) financial strain of COPD and (5) coping resources.

**Conclusions:** The overall findings illustrate the complex interaction between the experience of living with COPD and communication patterns, emotional states, social support and social roles within the family. The results highlight the need to develop family-based interventions to facilitate a functional adjustment to COPD. However, these interventions in COPD remain undeveloped and empirical evidence is needed.

**Key-words:** chronic obstructive pulmonary disease; family; impact; family-systems illness model; family-based interventions

## Introduction

According to the World Health Organization, 210 million people throughout the world are affected by chronic obstructive pulmonary disease (COPD) (World Health Organization, 2007). This incapacitating disease is estimated to become the seventh leading cause of years lived with disability by 2030 (Mathers & Loncar, 2006). COPD is characterised by persistent airflow limitation (Vestbo et al., 2013) and it is frequently associated with the occurrence of exacerbations, progressive loss of independence and poor quality of life. These aspects increase patients' dependence on family members, mainly on the carer who represents the primary source of support (Spence et al., 2008). Thus, a growing number of families have been dealing with the challenges imposed by COPD.

The associations between adult chronic diseases and family functioning are well-documented. It is known that a chronic illness has profound effects on close family members and on the family as a whole (Campbell, 2003; Knafl & Gilliss, 2002; Rolland, 1999). In addition, a growing body of research evidenced that families can have a beneficial or harmful influence on patient's psychological adjustment and illness management (Campbell, 2003; Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Rolland, 2003). Most research on COPD, however, has investigated its impacts solely on the patient (Barnett, 2005; Gardiner et al., 2010; Williams, Bruton, Ellis-Hill, & McPherson, 2007). Only a few number of studies have attempted to understand the nature and extent of the COPD impacts on family members, particularly, on those providing care (Bergs, 2002; Cain & Wicks, 2000; Pinto, Holanda, Medeiros, Mota, & Pereira, 2007; Simpson, Young, Donahue, & Rucker, 2010). However, according to our knowledge, no study has investigated the impacts of COPD on family life considering both the patient's and close family member's perceptions. The availability of this information is fundamental given the importance of family relationships in the management of chronic diseases and the bidirectional links between patient and family member outcomes.

Moreover, each chronic disease poses distinct challenges to families, and research needs to demarcate the disease's specificities (e.g., COPD) from the general aspects of chronic illnesses. Therefore, this study aimed to explore the perspectives of both patients and family members regarding the impact of COPD in their family life.

### **The Family Systems Illness Framework**

The Family Systems Illness (FSI) model (Rolland, 1984, 1987, 1999) can provide a useful framework to understand the experiences of families dealing with COPD. Rolland's framework has been used to explain the interactions between chronic diseases such as cancer, stroke, multiple sclerosis and pediatric chronic conditions and family functioning (Herzer et al., 2010; Rolland, 2005; Sieh, Dikkers, Visser-Meily, & Meijer, 2012). According to the FSI model, each family is affected by and influences the course of a chronic disease (Rolland, 1999). The model is grounded in a strength-oriented perspective, emphasising the possibilities for resilience and development of the family, instead of just considering their difficulties and risks (Walsh, 1996, 2003).

Rolland's FSI model postulates that family adjustment to chronic illness depends on the interplay of three dimensions: key family system variables; psychosocial typology of illness; and time phases of illness (Rolland, 1987, 1994). The model addresses how each type of disorder, with its pattern of emotional, practical and relational challenges over time, fits with the patterns, strengths and vulnerabilities of a family unit. It emphasises that family responses to chronic illness vary according to communication patterns, individual and family development, multigenerational patterns of coping with illness and loss and belief systems (Rolland, 2003, 2005).

The psychosocial typology of illness defines meaningful and useful categories with similar psychosocial demands for a wide set of chronic conditions affecting patients and families. It conceptualises broad distinctions of disease onset (acute or gradual), course (progressive,

constant or episodic), outcome (fatal or shorted life span, or possible sudden death vs. no effect on longevity), incapacitation (non-disabling vs. disabling) and the level of uncertainty about its trajectory. According to this psychosocial typology, COPD has a gradual onset, progressive course (with acute episodes), a possible fatal outcome and it is disabling (Rolland, 1987). To understand the natural history of chronic disease as a dynamic process, three time phases can be described (Rolland, 1994, 1999): crisis, chronic and terminal. The crisis phase comprises any symptomatic period before diagnosis and the initial contact with illness symptoms, treatments and institutional settings. The chronic phase, whether long or short, can be marked by constancy, progression or episodic change. It has been reported as “the day-to-day living with chronic illness”. The terminal phase includes the preterminal stage of the disease, where the inevitability of death becomes apparent and dominates the family life. Different phases require different tasks from the family, to facilitate a functional and healthy adjustment to the disease (Rolland, 1999).

Chronic diseases, such as COPD, are long-lasting conditions that require ongoing management over a period of years or decades (World Health Organization, 2005), becoming a part of the family identity (Larsen, 2009). Indeed, the chronic phase of the disease has been reported as the long haul, the time span between the initial diagnosis and readjustment period and the terminal phase (Rolland, 1999). The family perceives how the disease affects their life, and the task of keeping the balance between personal/family needs and illness constraints assumes significant importance. Family members reallocate roles and efforts on maintaining individual autonomy in the family system, to preserve a semblance of normality (Rolland, 1994). Considering that each time phase of an illness poses unique challenges to family functioning (Rolland, 1987, 1999, 2003), the FSI framework was used in this study to understand the psychosocial impacts of COPD on family life, during the chronic phase.

## **Methods**

## ***Design***

An exploratory qualitative study, with a cross-sectional design, was conducted with patients and family members in the chronic phase of COPD. Patients were included if they presented a COPD diagnosis for more than two years, according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria (Vestbo et al., 2013). The family member was identified by the patient as being the spouse, a child or a significant other. To participate, patients and family members had to meet the following criteria: age  $\geq 18$  years old; able to understand the purpose of the study and agree to participate voluntarily. Patients and family members were excluded if one of them presented severe psychiatric conditions and/or inability to understand and engage in the study.

The recruitment was performed in a primary care centre and in a district hospital in the central region of Portugal, between October 2011 and February 2012. Potentially eligible patients were identified by clinicians of the institutions involved in the study, who were then contacted via telephone by a clinician's assistance, who informed them about the study and asked for their willingness to be contacted by the researchers. Then, interested patients received a telephone call from the researchers, were informed in detail about the study objectives and were asked to identify eligible family members. For those who agreed to participate, a meeting was scheduled in the primary care centre or hospital, according to families' convenience. A total of 32 patients and their respective family members were contacted and informed about the study. All agreed to participate, however, 12 families failed the scheduled meeting due to deterioration of patients' health condition (e.g., COPD exacerbation). The final sample was composed of 40 participants, 20 patients and 20 family members.

## ***Data Collection***

A structured questionnaire was used to collect socio-demographic data from patients and family members (gender, age, academic qualifications, marital and work status). Additional

questions were included for family members to collect data related to the caregiving period (duration in years and hours per week) and kinship to the patient.

Spirometry was performed using a portable spirometer (MicroLab 3500, CareFusion, Kent, UK) to assess patients' lung function (Miller et al., 2005). The classification of COPD severity was carried out in accordance with the GOLD criteria (Vestbo et al., 2013). Patients were asked to report their disability resulting from breathlessness using the modified British Medical Research Council questionnaire (mMRC) (Doherty, 2006). The mMRC questionnaire comprises five grades (range 0–4), with higher grades indicating greater perceived respiratory disability.

Individual interviews were conducted to explore the perspectives of patients with COPD and their family members. The interview schedule comprised open-ended questions that were formulated around the impact of COPD in family life; specifically, patients and family members were asked: “*Which are the main changes that COPD brought to your personal and family life?*”; “*What are the main difficulties/concerns?*”; and “*How have you been coping with COPD?*”. The interviews were conducted at the same time but in different physical spaces, by two trained gerontologists, so patients and family members could talk openly and the confidentiality guaranteed. Participants were informed that they could interrupt the interview at any time. On average, the interviews with patients lasted  $46.7 \pm 4.8$  minutes and with family members  $50.7 \pm 5.3$  minutes. All interviews were digitally audio-recorded for further transcription and analysis.

### ***Ethical issues***

The study received full approval from the Institutional Ethics Committee. All participants in this study were unpaid volunteers. Written consent forms were obtained prior to any data collection. Some ethical concerns were considered regarding the nature of the interviews. It was expected that participants could be emotionally challenged during the interview, since



painful feelings about the COPD experience and how it constraints personal and family life are likely to arise in such context. For this reason, researchers informed participants that, in primary care centre and in the hospital, where the interviews were conducted, a psychologist was available to provide support in case of need. However, none of the participants gave a negative feedback about the interview nor expressed the wish to talk to the psychologist.

### ***Data Analysis***

Descriptive statistics were performed to characterise the sample, using PASW Statistics (Predictive Analytics Software) version 19.0 for Windows (SPSS Inc., Chicago, Illinois).

The interviews were transcribed verbatim. The transcripts were analysed using thematic analysis (Miles & Huberman, 1994). Two independent researchers (gerontologists) coded and categorised data into themes in three phases: data reduction; data display; and conclusion drawing/verification (Miles & Huberman, 1994). The data reduction intended to simplify the data by extracted themes. In this phase all transcripts were read, notes made, codes assigned, meanings grouped together and themes/subthemes generated. The data display allowed drawing conclusions. In this second phase, each researcher used maps of themes and quotations to facilitate data analysis. Conclusion drawing and verification implied reviewing the meaning of the analysed data and verifying emergent conclusions as a means of testing the validity of the findings (Miles & Huberman, 1994). After the three phases, check-coding was conducted between the two researchers to compare and discuss the themes generated. They subsequently registered their agreements and disagreements. Inter-judgment agreement was 80%, which may be considered high (Miles & Huberman, 1994). After discussing, researchers reached a consensus on the major themes and subthemes that emerged from the data. To assure credibility of qualitative data the *peer debriefing* technique was also performed (Lincoln & Guba, 1985). This technique consists of reviewing the methodology procedures and the data by an independent researcher to the study, who challenges the

researchers' assumptions and ask questions about the method and interpretations. This procedure allowed the research team to become more aware of their own views and helped limiting the potential influence of preconceptions regarding the data (Creswell & Miller, 2000; Lincoln & Guba, 1985).

To ensure reflexivity (Meyrick, 2006), the researchers held regular group meetings to reflect and discuss issues related to the study. All research team members had experience in working with families living with chronic illness, but none had personally experienced a COPD diagnosis or lived with a family member with this condition.

## **Findings**

### ***Participants***

Patients were mostly male ( $n=16$ ; 80%), with a mean age of  $74.1\pm8.5$  years old. Patients' mean forced expiratory volume in one second ( $FEV_1$ ) was  $37.3\pm8.4\%$  of the predicted. According to the GOLD criteria, 14 patients had severe COPD (70%) and 6 very severe (30%) (Vestbo et al., 2013). Patients with very severe COPD were on long-term oxygen therapy. Most patients ( $n=12$ ; 60%) had a mMRC grade of 3 (*"Stops for breath after walking about 100 meters or after a few minutes on level ground"*).

Family members were twelve spouses and eight adult children, with a mean age of  $61.5\pm13.1$  years old. Most were female ( $n=18$ ; 90%), lived with the patients ( $n=16$ ; 80%) and half provided more than 20 hours of care per week.

Table 1 provides the socio-demographic, clinical and caregiving characteristics of participants.

[Table 1 near here]

From the 40 transcripts, different significant themes and subthemes were identified regarding the impact of the chronic phase of COPD on personal and family life, according to patients'

and family members' perspectives (table 2). Participants' identification was coded (p-patients; fm-family members) to preserve anonymity and ensure confidentiality.

[Table 2 near here]

### ***Patients' perspectives***

#### *Impact of COPD symptoms on personal and family daily life*

All patients (n=20) reported negative impacts of the COPD symptoms (e.g., breathlessness, fatigue) in their daily life, namely: restriction in leisure and social activities, such as walking or dancing; constraints in mobility; sleep disturbance and restrictions in professional activity, forcing them to retire from their employment. These impacts were reflected in the following statements: *"I used to enjoy going out dancing. Nowadays I go, but I am not the same person, I feel tired, I can only watch the others dancing."* [p<sub>1</sub>, female, 73yrs]; *"I wish I could do more things, I wish I could go to work but I know that this [disease] will end up with me."* [p<sub>2</sub>, male, 58yrs]

Moreover, negative impacts on family activities, such as going on holidays or visiting other family members, were also reported by patients. Due to these changes, patients felt restricted to their home: *"I don't go to my relatives' house, I don't go on vacations, I'm restricted to my home."* [p<sub>3</sub>, male, 80yrs] These restrictions were often accompanied by patients' feelings of sadness and loneliness: *"There are some days that I prefer to be alone, in those days, I have no joy to go out."* [p<sub>4</sub>, male, 66yrs]

#### *(Over)Protective family support*

Most patients stated that their family members were a source of support, either instrumental or emotional, and were responsive to their needs (n=16): *"She [wife] is always by my side for everything that happens."* [p<sub>2</sub>, male, 58yrs] Nevertheless, patients felt that their family

247 members were excessively focused on their disease and permanently concerned with their  
248 health behaviours. This type of family support was sometimes perceived by patients as  
249 overprotective: *"The care and concern are excessive; she [wife] is extremely concerned with*  
250 *me."* [p5, male, 66yrs]

#### 251 *Difficulties in couple communication*

252 Patients considered that COPD had an impact on marital relationship, affecting couple's  
253 communication (n=7). Most male patients expressed embarrassment when asking their wives  
254 for help in activities of daily living: *"She [wife] helps me with everything, but most of the*  
255 *times I do not ask for help because I feel embarrassed."* [p7, male, 77yrs] Feelings of not  
256 being understood by the partner were also present: *"I feel that sometimes I am a little bit*  
257 *aggressive in my answers, but she [wife] needs to understand my problems. She doesn't*  
258 *understand me!"* [p6, male, 60yrs]

#### 259 *Sense of identity loss*

260 The difficulty to accept the disease led to a sense of identity loss in some patients (n=6): *"I*  
261 *used to do everything and now I can't do any of those things, I'm reduced to nothing."* [p8,  
262 male, 70yrs] Patients' loss of identity was associated with feelings of powerlessness and  
263 difficulty to redefine their role in the family, expressed by difficulties in being reciprocal:  
264 *"Now I can't do a thing for them [family], my wife is the leader and she is responsible for*  
265 *everything."* [p9, male, 79yrs] Patients were also concerned about the family reactions to their  
266 losses: *"I'm not the person I used to be (...) my family feels sad to see me this way."* [p10,  
267 female, 60yrs]

#### 268 *Fear of COPD progression*

269 Patients expressed their fear about the progression of the disease, mainly due to the worsening  
270 of symptoms, like breathlessness (n=12): *"(...) with the disease progression, this shortness of*

271 *breath gets worse and now, I think a lot about tomorrow, the pain that it might cause.” [p<sub>11</sub>,*  
272 *male, 64yrs]*

### 273 *Coping resources*

274 Patients relied on several coping strategies to deal with COPD and their constraints, namely  
275 positive reappraisal, search for meaning and problem-solving strategies. Reminding  
276 themselves that things could be worse and they were well-off compared to other people were  
277 some of the coping skills used by patients (n=4): *“We have to think about our day-to-day*  
278 *lives and think that there is always someone else that is worse than us.” [p<sub>13</sub>, female, 88yrs]*

279 Patients also searched for logical causes of COPD, attributing it to past experiences (e.g.,  
280 childhood illness) (n=2): *“I have realised that this [disease] was due to having bronchitis*  
281 *when I was young, and then smoking (...) I was born and raised next to the lagoon and I am*  
282 *starting to realise that probably this affected me as well.” [p<sub>12</sub>, male, 77yrs]*

283 Problem-solving strategies were also used by patients. Maintaining a healthy lifestyle through  
284 protective behaviours and exercising regularly were two of the most widely used strategies  
285 (n=6): *“I need to get vaccinated. Vaccines have already prevented me from catching the flu”*  
286 *[p<sub>13</sub>, female, 88yrs]; “I started swimming again, I hope it is the best for my disease” [p<sub>14</sub>,*  
287 *male, 69yrs]*

### 288 ***Family members’ perspectives***

#### 289 *Restrictions in family’s social life*

290 Given the demands of the disease, family members felt that the patient required more  
291 attention and care, leading to restrictions in their social life (n=18): *“I gave up things that*  
292 *could make me happy outside the home.” [fm<sub>2</sub>, wife, 66yrs]* Specifically, the spouses reported  
293 an increased interaction with the patient but a reduction in personal contacts with other family  
294 members: *“I stay at home instead of going out with my sisters. Now we talk more on the*

295 *phone, I'm living a very isolated life.*" [fm<sub>1</sub>, wife, 66yrs] Moreover, some spouses also  
296 revealed that they felt limited to home due to patient's dependence of oxygen therapy: "*I tell*  
297 *you, my house is my prison.*" [fm<sub>6</sub>, wife, 65yrs]; "*Walking down the street with him is quite*  
298 *problematic! We end up staying at home, so my life turned upside down. He doesn't feel*  
299 *good*" [fm<sub>2</sub>, wife, 66yrs] COPD also changed family routines, causing a restriction in their  
300 leisure activities: "*We don't go for a walk, on vacations, family reunions have ended. We are*  
301 *very isolated.*" [fm<sub>7</sub>, wife, 75yrs]

### 302 *Emotional distress related to COPD exacerbations*

303 The progressive trajectory of COPD, combined with episodes of acute exacerbation, was a  
304 major cause of emotional distress for family members (n=15): "*Everything changes, our lives*  
305 *turned upside down in all aspects, all! In terms of emotional states (...) our lives stopped!*"  
306 [fm<sub>1</sub>, wife, 66yrs]

307 Emotional distress was mainly related to the worsening of patients' symptoms and the  
308 perceived possibility of patients to have a very painful death associated to asphyxia: "*I get*  
309 *always frightened when she is short of breath, and then I fear that she might die.*" [fm<sub>5</sub>,  
310 daughter, 43yrs] In the former, family members shared their permanent concerns regarding  
311 the patient's health condition, leading to an extreme attention to environmental factors, such  
312 as climate, but also with patients' proper clothing: "*It is a constant concern, I'm always afraid*  
313 *that he gets the flu. I know that it is the beginning of a respiratory infection, and it all just*  
314 *gets worse.*" [fm<sub>2</sub>, wife, 66yrs] The fear of a painful death due to asphyxia led family  
315 members to be permanently close to the patient, avoiding leaving her/him alone: "*I feel*  
316 *worried all the time, I cannot let him at home by himself, because something can happen.*"  
317 [fm<sub>4</sub>, daughter, 50yrs]

### 318 *Tension in couple relationship*

319 Similarly to patients, spouses also reported constraints in the couple relationship (n=5).  
320 Spouses blamed the patient for the COPD diagnosis due to life-cycle smoking habits, causing  
321 disagreement and tension between the couple: *"In relation to his addictions [smoking], he is*  
322 *a weak-minded person."* [fm9, wife, 75yrs]

323 Marital tensions were also caused by patient's resistance to use portable oxygen therapy: *"He*  
324 *is embarrassed to go out with a bottle of oxygen, this situation has been discussed. He always*  
325 *upsets me (...) then he begins: this is heavy, this is heavy"* [fm1, wife, 66yrs]

326 Family members believed that patients' attitudes and negative emotional reactions to the  
327 disease caused tensions in daily life: *"He continues to do things, but his behaviour has*  
328 *changed. I think he is more aggressive, because he cannot deal with the situation."* [fm8,  
329 wife, 78yrs]

#### 330 *Financial strain of COPD*

331 Two family members reported that COPD had limited patients' ability to work and forced  
332 their retirement, affecting the family's financial resources: *"He stopped working, so our*  
333 *economic situation got a lot worse."* [fm2, wife, 66yrs] Financial strain was also caused by the  
334 need of expensive medications (e.g., bronchodilators) with no support from social and health  
335 services: *"These medications are expensive and there is no support from the services."* [fm10,  
336 husband, 62yrs]

#### 337 *Coping resources*

338 Similarly to patients, family members used a number of coping strategies to handle with the  
339 difficulties imposed by COPD. Family members dealt with COPD through positive  
340 reappraisal (n=9). Living with and caring for a patient with COPD allowed family members to  
341 find meaning in their experience, as they considered it as an opportunity for personal growth  
342 from adversity: *"I changed as a person (...) the disease makes me feel more mature, more*

343 *prepared and responsible for other people."* [fm<sub>10</sub>, husband, 62yrs]; *"Certainly we grow up*  
344 *with these difficulties; perhaps we look more at what surrounds us, is a way for us to grow*  
345 *spiritually."* [fm<sub>11</sub>, wife, 79yrs]

346 Getting help and support from family, friends and professional networks were some of the  
347 mechanisms used to manage COPD constraints (n=17): *"When my wife was hospitalised, he*  
348 *helped me* [grandson]! *'Grandpa, don't worry, I will cook something'"* [fm<sub>10</sub>, husband,  
349 62yrs]; *"I have too many friends that call me, that give me support and say: 'keep calm, you*  
350 *know, it is going to be alright'"* [fm<sub>6</sub>, wife, 65yrs]

351 Family members applied other problem-solving strategies, such as seeking for relevant  
352 information about COPD and treatment procedures (n=4), or reorganising family routines to  
353 minimise the effects of potentially adverse COPD effects for the patient (e.g., change the  
354 place of family meetings) (n=6): *"I know what is like, she gets tired and I try to avoid her*  
355 *doing things, I do them instead. Like bed-making, lift the mattress, she has difficulties and I*  
356 *help her."* [fm<sub>10</sub>, husband, 62yrs]

## 357 **Discussion**

358 The overall findings illustrate the complex interaction between the experience of living with  
359 COPD and communication patterns, emotional states, social support and social role within the  
360 family. Although some different reactions to COPD were identified, patients and family  
361 members shared similar and interrelated difficulties and concerns that seemed to affect family  
362 functioning.

363 Restraints in family social life represented a significant lifestyle change for both patients and  
364 family members as a result of the spiral of worsening COPD symptoms. Patients felt deprived  
365 from family and social activities as a consequence of the progressive COPD-related fatigue,  
366 sleep disturbance, breathlessness and difficulty in mobility. Hence, it is known that patients



367 become socially isolated and do not share experiences with family and friends, which  
368 frequently lead to feelings of sadness, loneliness or even abandonment (Ek & Ternestedt,  
369 2008; Gardiner et al., 2010). But the confining/isolating nature of COPD was also extended to  
370 their family members. This result is not surprising, as while the dependency of the ill person  
371 increases, the caring demands from close family members also intensify (e.g., monitoring  
372 breathlessness, long-term oxygen therapy and treatment regimen adherence) forcing them to  
373 give up from social contacts and activities (Bergs, 2002; Booth, Silvester, & Todd, 2003).  
374 Consistent with previous research (Boyle, 2009; Gullick, 2012; Simpson et al., 2010), the  
375 patient's need for oxygen therapy was pointed out as a particular reason for family members'  
376 restrictions in social life. Moreover, for family members, the majority of social interactions  
377 were limited to the ill person. Due to time constraints and COPD care demands, family  
378 members may perceive little opportunity to maintain or develop new social relationships. It  
379 has been widely recognised that the loss of social participation of family members,  
380 particularly the carers, contribute to high levels of perceived burden and other negative  
381 health-related outcomes (Croog, Burleson, Sudilovsky, & Baume, 2006; Pearlin, Mullan,  
382 Semple, & Skaff, 1990; Thommessen et al., 2002). Moreover, families exposed to long-term  
383 illness demands tend to define themselves based almost exclusively in that experience; this  
384 reorganisation of family dynamics around the illness and the difficult emotional landscape  
385 that surrounds it, can rigidify the family functioning and development as a chronically ill  
386 family (Patterson & Garwick, 1994). Thus, as recommended by the FSI Model, interventions  
387 should be implemented to help family members coping with the developmental demands of  
388 the disease, without sacrificing their own or family's development as a system over time  
389 (Rolland, 2003). Moreover, raising community awareness for the availability of respite  
390 services is fundamental for family members to maintain and nurture personal social networks,  
391 enhance social support, preserve personal freedom and enable self-care.

392 The couple relationship appears to have been affected by the disease. According to the  
393 patients' views, the poor supportive attitudes of spouses, such as lack of validation for the  
394 patient's negative emotional reactions, overprotection or criticism, can suggest marital-  
395 strained relationships (Bergs, 2002; Grant, Cavanagh, & Yorke, 2012; Simpson et al., 2010).  
396 A significant amount of research across different chronic illnesses (e.g., heart disease, cancer  
397 or chronic kidney disease) has demonstrated that poor quality spousal support, like critical,  
398 blaming and controlling behaviours, are predictors of patients' poor physical and mental  
399 health outcomes and reduce the ability to cope with the disease (Campbell, 2003; Martire et  
400 al., 2004). In the present study, beliefs about the causes of COPD were particularly significant  
401 for family members. Some spouses tended to blame the partners for their disease, as a result  
402 of long years of cigarette smoking. Perceiving COPD as a self-inflicted disease may create  
403 tension in the couple relationship that might lead to marital conflict and turn the caring  
404 responsibility harder to accept (Gullick, 2012).

405 In addition, empirical evidence suggests that those who feel burdened by caregiving tend to  
406 behave overprotectively (Kuijer et al., 2000; Thompson & Sobolew-Shubin, 1993). This is  
407 particularly the case of female carers who tend to be more overprotective than male carers  
408 (Edwards & Noller, 1998; Holtzman, Abbey, Singer, Ross, & Stewart, 2011). Spouses'  
409 overprotection however, has been shown to undermine patients' self-efficacy in dealing with  
410 the disease and patients' feelings of control over their lives (Hagedoorn et al., 2000; Martire,  
411 Stephens, Druley, & Wojno, 2002). Such evidence might explain a sense of loss of identity  
412 and the feelings of powerlessness expressed by patients, particularly men, who had also  
413 difficulties in redefining their roles within the family. Therefore, it is essential to improve  
414 open communication between patients and family members about the support that is needed,  
415 perceived and provided. Professionals should inform families about the possible maladaptive  
416 effects of blaming, controlling and overprotecting and help them to redefine relationships

with others, as well as, to preserve the concept of personal and family identity (Rolland, 1999, 2003).

The likelihood and severity of COPD-related crisis was particularly distressful for family members who were often too worried to leave the patient in case of an acute breathlessness episode occur in their absence. Fears about this illness-related crisis are often considered a major source of a family's undercurrent of anxiety (Boyle, 2009; Grant et al., 2012; Pinto et al., 2007; Spence et al., 2008). Concerns related to the disease progression and worsening of symptoms were also expressed by patients. Family feelings of anticipatory loss were associated with the uncertainty about COPD prognosis. These findings are consistent with previous studies reporting that patients with COPD tend to be poorly informed about the long-term prognosis of their disease and about what to expect toward the end of life, especially when compared with other diseases such as cancer or acquired immunodeficiency syndrome (Curtis et al., 2002; Gardiner et al., 2010). According to the FSI model, learning to live with anticipatory loss and uncertainty, as for the case of COPD trajectory, is a fundamental task for families in the chronic phase (Rolland, 1999). Thus, family-based interventions should seek suitable ways of normalising emotions related to threatened or impending loss, strengthening the families' capacities to cope with emotional distress. In addition, developing viable and flexible plans is crucial for families to cope with possible crises, highlighting the need to be offered with useful information and guidelines about the COPD course and symptom management (Rolland, 1994).

Despite the adverse effects of COPD, patients and family members mobilised their resources and strengths to cope with the difficulties of everyday life. Some of them were able to find meaning in COPD experience, using positive reappraisal. Problem-solving strategies were also reported from both sides. In other chronic conditions, evidence has shown that the use of positive reappraisal, seek guidance and support, and problem-solving strategies were

positively related to psychological growth and development (Kramer, 1997; Rohrbaugh et al., 2004; Urcuyo, Boyers, Carver, & Antoni, 2005; Widows, Jacobsen, Booth-Jones, & Fields, 2005). As such, family-based interventions in the COPD context should be focused on family coping and adaptational pathways, to reduce vulnerability and facilitate a positive adaptation (e.g. psychoeducational multifamily groups) (Rolland, 1994; Walsh, 2002). Moreover, professionals should give families positive feedback from successful experiences of coping, since it strengthens the COPD family resources (Moos & Holahan, 2007). The FSI model acknowledges the importance of these resources to a functional adjustment to the disease (Rolland, 2003).

### ***Limitations and future research perspectives***

Some limitations need to be acknowledged. This study was conducted with families in the chronic phase of the disease. However, the different time-phases in COPD - crisis and terminal - might involve different specific impacts on COPD families that need to be further explored. Moreover, the cross-sectional design is limited to provide an understanding of the changing nature of COPD impacts and challenges for families. Specifically, it does not allow an understanding of how the transition periods between the three time phases might be experienced. Future longitudinal studies need to be conducted to examine changes throughout the course of the disease. Analysing patient and family member's experiences together and relating these with their history of family functioning should also be further explored. It would help to identify high risk families that, shaped by unresolved issues and past dysfunctional patterns, might not functionally cope with the challenges imposed by a severe chronic condition such as COPD (Rolland, 1994). Moreover, the sample recruitment might have resulted in an over-representation of distressed families, as clinicians might have identified those participants who could somehow benefit from a "psychosocial-oriented interview". Finally, the findings were also limited by cohort and contextual factors.

Participants were mostly older adults and the study was conducted in Portugal, where health and support services for patients with COPD and their families (e.g., pulmonary rehabilitation, respite care or psychoeducational support) are not widespread (Figueiredo, Gabriel, Jácome, & Marques, 2013). Thus, cross-cultural studies with samples including younger cohorts should also be conducted to explore the extent of these findings.

Nevertheless, the current study provides relevant and unique knowledge about the difficulties, constraints and resources experienced by families in the presence of COPD. The overall findings highlight the need for developing supportive family-based interventions in the context of COPD. Priority goals should include: helping families to cope with and manage the stresses inherent to COPD; increasing mutually supportive interactions between members; nurturing the current support system and build additional extra familial support; and minimising intrafamilial hostility and criticism (Fisher & Weihs, 2000; Weihs, Fisher, & Baird, 2002). Family-focused approaches to the management of chronic diseases have been shown promising results in a number of patient and family member outcomes (Martire et al., 2004; Shields, Finley, Chawla, & Meadors, 2012). However, the effects of family-based interventions targeted to the management of COPD remains unknown (Fisher & Weihs, 2000) and empirical evidence is needed.

## **Conclusion**

The presence of a chronic illness like COPD can deeply affect not only the patient, but also the family. The overall results showed that COPD families face a number of difficulties related to relationships tension, social isolation, a sense of powerlessness, emotional strain and uncertainty towards the future. In the light of the FSI model (Rolland, 1987, 1999) it becomes clear that there are a number of challenges that families need to pursuit in order to “put the illness in its place” and keep going with their individual and familiar lives throughout

the “long haul” (Rolland, 1999). Therefore, the results highlight the need to develop family-based interventions to facilitate a functional adjustment to the COPD.

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### References

- Barnett, M. (2005). Chronic obstructive pulmonary disease: a phenomenological study of patients’ experiences. *Journal of Clinical Nursing, 14*(7), 805-812. doi: 10.1111/j.1365-2702.2005.01125.x
- Bergs, D. (2002). ‘The Hidden Client’– women caring for husbands with COPD: their experience of quality of life. *Journal of Clinical Nursing, 11*(5), 613-621. doi: 10.1046/j.1365-2702.2002.00651.x
- Booth, S., Silvester, S., & Todd, C. (2003). Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. *Palliat Support Care, 1*(4), 337-344. doi: 10.1017/S1478951503030499
- Boyle, A. H. (2009). An integrative review of the impact of COPD on families. *South Online J Nurs Res, 9*(3), 1-12.
- Cain, C. J., & Wicks, M. N. (2000). Caregiver Attributes as Correlates of Burden in Family Caregivers Coping With Chronic Obstructive Pulmonary Disease. *Journal of Family Nursing, 6*(1), 46-68. doi: 10.1177/107484070000600104
- Campbell, T. L. (2003). The effectiveness of family interventions for physical disorders. *Journal of Marital and Family Therapy, 29*(2), 263-281. doi: 10.1111/j.1752-0606.1995.tb00178.x

515 Creswell, J. W., & Miller, D. L. (2000). Determining Validity in Qualitative Inquiry. *Theory*  
516 *Into Practice*, 39(3), 124-130. doi: 10.1207/s15430421tip3903\_2

517 Croog, S. H., Burleson, J. A., Sudilovsky, A., & Baume, R. M. (2006). Spouse caregivers of  
518 Alzheimer patients: problem responses to caregiver burden. *Aging & Mental Health*,  
519 10(2), 87-100. doi: 10.1080/13607860500492498

520 Curtis, J. R., Wenrich, M. D., Carline, J. D., Shannon, S. E., Ambrozy, D. M., & Ramsey, P.  
521 G. (2002). Patients' perspectives on physician skill in end-of-life care: differences  
522 between patients with COPD, cancer, and AIDS. *Chest*, 122(1), 356-362. doi:  
523 10.1378/chest.122.1.356

524 Doherty, D. E., et al. (2006). *Chronic Obstructive Pulmonary Disease: Consensus*  
525 *Recommendations for Early Diagnosis and Treatment*. Journal of Family Practice.

526 Edwards, H., & Noller, P. (1998). Factors Influencing Caregiver-Care Receiver  
527 Communication and Its Impact on the Well-Being Older Care Receivers. *Health*  
528 *Communication*, 10(4), 317-341. doi: 10.1207/s15327027hc1004\_2

529 Ek, K., & Ternstedt, B.-M. (2008). Living with chronic obstructive pulmonary disease at the  
530 end of life: a phenomenological study. *Journal of Advanced Nursing*, 62(4), 470-478.  
531 doi: 10.1111/j.1365-2648.2008.04611.x

532 Figueiredo, D., Gabriel, R., Jácome, C., & Marques, A. (2013). Caring for people with early  
533 and advanced chronic obstructive pulmonary disease: how do family carers cope?  
534 *Journal of Clinical Nursing*, 23(1-2), 211-220. doi: 10.1111/jocn.12363

535 Fisher, L., & Weihs, K. L. (2000). Can addressing family relationships improve outcomes in  
536 chronic disease? Report of the National Working Group on Family-Based  
537 Interventions in Chronic Disease. *The Journal Of Family Practice*, 49(6), 561-566.

538 Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., . . . Seamark, D. (2010).  
539 Exploring the care needs of patients with advanced COPD: An overview of the  
540 literature. *Respiratory Medicine*, 104(2), 159-165. doi: 10.1016/j.rmed.2009.09.007

- Grant, M., Cavanagh, A., & Yorke, J. (2012). The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: A narrative review. *International Journal of Nursing Studies*, 49(11), 1459-1471. doi: 10.1016/j.ijnurstu.2012.02.010
- Gullick, J. (2012). Psychosocial Dimensions of COPD for the Patient and Family. In Kian-Chung Ong (Ed.), *Chronic Obstructive Pulmonary Disease- Current Concepts and Practice* (pp. 153-178).
- Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbles, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology*, 19(3), 274-282. doi: 10.1037/0278-6133.19.3.274
- Herzer, M., Godiwala, N., Hommel, K. A., Driscoll, K., Mitchell, M., Crosby, L. E., . . . Modi, A. C. (2010). Family functioning in the context of pediatric chronic conditions. *J Dev Behav Pediatr*, 31(1), 26-34. doi: 10.1097/DBP.0b013e3181c7226b
- Holtzman, S., Abbey, S. E., Singer, L. G., Ross, H. J., & Stewart, D. E. (2011). Both patient and caregiver gender impact depressive symptoms among organ transplant caregivers: Who is at risk and why? *Journal of Health Psychology*, 16(5), 843-856. doi: 10.1177/1359105310393542
- Knafl, K. A., & Gilliss, C. L. (2002). Families and Chronic Illness: A Synthesis of Current Research. *Journal of Family Nursing*, 8(3), 178-198. doi: 10.1177/107484070200800302
- Kramer, B. J. (1997). Differential Predictors of Strain and Gain Among Husbands Caring for Wives With Dementia. *The Gerontologist*, 37(2), 239-249. doi: 10.1093/geront/37.2.239
- Kuijer, R. G., Ybema, J. F., Buunk, B. P., De Jong, G. M., Thijs-Boer, F., & Sanderman, R. (2000). Active Engagement, Protective Buffering, and Overprotection: Three Ways of



567 Giving Support by Intimate Partners of Patients with Cancer. *Journal of Social and*  
568 *Clinical Psychology*, 19(2), 256-275. doi: 10.1521/jscp.2000.19.2.256

569 Larsen, P. D. (2009). Chronicity. In Lubkin IM & Larsen PD (Eds.), *Chronic Illness: Impact*  
570 *and Interventions* (7th ed.). Sudbury, MA: Jones and Bartlett Publishers.

571 Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

572 Martire, L. M., Lustig, A. P., Schulz, R., Miller, G. E., & Helgeson, V. S. (2004). Is it  
573 beneficial to involve a family member? A meta-analysis of psychosocial interventions  
574 for chronic illness. *Health Psychol*, 23(6), 599-611. doi: 10.1037/0278-6133.23.6.599

575 Martire, L. M., Stephens, M. A. P., Druley, J. A., & Wojno, W. C. (2002). Negative Reactions  
576 to Received Spousal Care: Predictors and Consequences of Miscarried Support.  
577 *Health Psychology*, 21(2), 167-176. doi: 10.1037/0278-6133.21.2.167

578 Mathers, C. D., & Loncar, D. (2006). Projections of Global Mortality and Burden of Disease  
579 from 2002 to 2030. *PLoS Medicine*, 3(11), 2011-2030. doi:  
580 10.1371/journal.pmed.0030442

581 Meyrick, J. (2006). What is Good Qualitative Research?: A First Step towards a  
582 Comprehensive Approach to Judging Rigour/Quality. *Journal of Health Psychology*,  
583 11(5), 799-808. doi: 10.1177/1359105306066643

584 Miles, M. B., & Huberman, M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*.  
585 Newbury Park: Sage.

586 Miller, M. R., Hankinson, J., Brusasco, V., Burgos, F., Casaburi, R., Coates, A., . . . Wanger,  
587 J. (2005). Standardisation of spirometry. *European Respiratory Journal*, 26(2), 319-  
588 338. doi: 10.1183/09031936.05.00034805

589 Moos, R. H., & Holahan, C. J. (2007). Adaptive tasks and methods of coping with illness and  
590 disability. In E. Martz & H. Livneh (Eds.), *Coping with chronic illness and disability:*  
591 *Theoretical, empirical, and clinical aspects* (pp. 107-126). New York: Springer.

592 Patterson, J. M., & Garwick, A. W. (1994). The impact of chronic illness on families: A  
 593 family systems perspective. *Annals of Behavioral Medicine*, 16(2), 131-142.

594 Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress  
 595 process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583-  
 596 594. doi: 10.1093/geront/30.5.583

597 Pinto, R. A., Holanda, M. A., Medeiros, M. M. C., Mota, R. M. S., & Pereira, E. D. B. (2007).  
 598 Assessment of the burden of caregiving for patients with chronic obstructive  
 599 pulmonary disease. *Respiratory medicine*, 101(11), 2402-2408. doi:  
 600 10.1016/j.rmed.2007.06.001

601 Rohrbaugh, M. J., Shoham, V., Coyne, J. C., Cranford, J. A., Sonnega, J. S., & Nicklas, J. M.  
 602 (2004). Beyond the "Self in Self-Efficacy: Spouse Confidence Predicts Patient  
 603 Survival Following Heart Failure. *Journal of Family Psychology*, 18(1), 184-193. doi:  
 604 10.1037/0893-3200.18.1.184

605 Rolland, J. S. (1984). Toward a psychosocial typology of chronic and life-threatening illness.  
 606 *Family Systems Medicine*, 2(3), 245-262. doi: 10.1037/h0091663

607 Rolland, J. S. (1987). Chronic Illness and the life cycle: a conceptual framework. *Family*  
 608 *Process*, 26, 203-221. doi: 10.1111/j.1545-5300.1987.00203.x

609 Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New  
 610 York: Basic Books.

611 Rolland, J. S. (1999). Parental Illness and disability: a family systems framework. *Journal of*  
 612 *family therapy*, 21, 242-266. doi: 10.1111/1467-6427.00118

613 Rolland, J. S. (2003). Mastering Family Challenges in Illness and Disability. In F. Walsh  
 614 (Ed.), *Normal Family Processes* (3rd ed.). New York: Guilford.

615 Rolland, J. S. (2005). Cancer and the family: An integrative model. *Cancer*, 104(S11), 2584-  
 616 2595. doi: 10.1002/cncr.21489

- Shields, C. G., Finley, M. A., Chawla, N., & Meadors, w. P. (2012). Couple and Family Interventions in Health Problems. *Journal of Marital and Family Therapy*, 38(1), 265-280. doi: 10.1111/j.1752-0606.2011.00269.x
- Sieh, D. S., Dikkers, A. L. C., Visser-Meily, J. M. A., & Meijer, A. M. (2012). Stress in Adolescents with a Chronically Ill Parent: Inspiration from Rolland's Family Systems-Illness Model. *Journal of Developmental and Physical Disabilities*, 24(6), 591-606. doi: 10.1007/s10882-012-9291-3
- Simpson, A. C., Young, J., Donahue, M., & Rucker, G. (2010). A day at a time: caregiving on the edge in advanced COPD. *International journal of chronic obstructive pulmonary disease*, 5, 141-151. doi: 10.2147/COPD.S9881
- Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B., & Watson, B. (2008). Active carers: living with chronic obstructive pulmonary disease. *International journal of palliative nursing*, 14(8), 368-372.
- Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A. R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal Of Geriatric Psychiatry*, 17(1), 78-84. doi: 10.1002/gps.524
- Thompson, S. C., & Sobolew-Shubin, A. (1993). Overprotective Relationships: A Nonsupportive Side of Social Networks. *Basic and Applied Social Psychology*, 14(3), 363-383. doi: 10.1207/s15324834basp1403\_8
- Urcuyo, K. R., Boyers, A. E., Carver, C. S., & Antoni, M. H. (2005). Finding benefit in breast cancer: Relations with personality, coping, and concurrent well-being. *Psychology & Health*, 20(2), 175-192. doi: 10.1080/08870440512331317634
- Vestbo, J., Hurd, S. S., Agustí, A. G., Jones, P. W., Vogelmeier, C., Anzueto, A., . . . Rodriguez-Roisin, R. (2013). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. *American Journal of*

*Respiratory and Critical Care Medicine*, 187(4), 347-365. doi: 10.1164/rccm.201204-0596PP

Walsh, F. (1996). The Concept of Family Resilience: Crisis and Challenge. *Family Process*, 35(3), 261-281. doi: 10.1111/j.1545-5300.1996.00261.x

Walsh, F. (2002). A Family Resilience Framework: Innovative Practice Applications. *Family Relations*, 51(2), 130-137. doi: 10.1111/j.1741-3729.2002.00130.x

Walsh, F. (2003). Changing families in a changing world. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed ed., pp. 3-26). New York: Guilford Press.

Weihs, K., Fisher, L., & Baird, M. (2002). Families, health, and behavior - A section of the Commissioned Report by the Committee on Health and Behavior: Research, Practice, and Policy. *Families, Systems and Health*, 20(1), 7-46.

Widows, M. R., Jacobsen, P. B., Booth-Jones, M., & Fields, K. K. (2005). Predictors of posttraumatic growth following bone marrow transplantation for cancer. *Health Psychol*, 24(3), 266-273. doi: 10.1037/0278-6133.24.3.266

Williams, V., Bruton, A., Ellis-Hill, C., & McPherson, K. (2007). What really matters to patients living with chronic obstructive pulmonary disease? An exploratory study. *Chronic Respiratory Disease*, 4(2), 77-85. doi: 10.1177/1479972307078482

World Health Organization. (2005). *Preparing a health care workforce for the 21st century: the challenge of chronic conditions*. Geneva: World Health Organization.

World Health Organization. (2007). *Global surveillance, prevention and control of chronic respiratory diseases : a comprehensive approach*. Geneva: World Health Organization.

667 **Table 1** - Socio-demographic, clinical and caregiving characteristics of participants (n=40).

Characteristics	Patients (n=20)	Family members (n=20)
<b>Gender</b>		
Female, n(%)	4(20%)	18(90%)
Male, n(%)	16(80%)	2(10%)
<b>Age (years), M±SD</b>	74.1±8.5(58-88)	61.5±13.0(38-81)
<b>Academic qualifications, n(%)</b>		
No qualifications	2(10%)	2(10%)
Primary School	13(65%)	12(60%)
Secondary School	5(25%)	5(25%)
High school	0	1(5%)
<b>Marital Status, n(%)</b>		
Married	15(75%)	19(95%)
Divorced	1(5%)	1(5%)
Widowed	4(20%)	0
<b>Work status, n(%)</b>		
Retirement	19(95%)	11(55%)
Full-time employment	1(5%)	5(25%)
Unemployment	0	2(10%)
Domestic	0	2(10%)
<b>FEV<sub>1</sub> (% predicted), M±SD</b>	37.3±8.4%	-
<b>mMRC, n(%)</b>		
Grade 1	4(20%)	-
Grade 2	4(20%)	-
Grade 3	12(60%)	-
<b>Caregiving hours (weekly hours), n(%)</b>		
8-20	-	10(50%)
20-40	-	4(20%)
>40	-	6(30%)

668 Abbreviations: FEV<sub>1</sub>, forced expiratory volume in one second; mMRC, modified British Medical Research Council  
669 questionnaire.

671 **Table 2** - Living in the chronic phase of COPD: emerging themes and subthemes from the patients' and family members'  
672 perspectives.

<b>Psychosocial typology of COPD, according to the FSI Model</b>		Gradual onset, progressive course (with acute episodes), a possible fatal outcome and incapacitating.
<b>Time phase of COPD</b>		Chronic phase
<i>Patients' perspectives</i>	Themes	Subthemes
	<b>Impact of COPD symptoms on personal and family daily life</b>	Restrictions in leisure and social activities
		Constraints in mobility
		Sleep disturbance
	<b>(Over)Protective family support</b>	Restrictions in professional activity
		Family as a source of support
	<b>Difficulties in couple communication</b>	(Over)Protective care
		Embarrassment of asking for help
		Feelings of not being understood
	<b>Sense of identity loss</b>	Feelings of powerlessness
		Difficulties in being reciprocal
	<b>Fear of COPD progression</b>	Worsening of symptoms
		Positive reappraisal
	<b>Coping resources</b>	Search for meaning
		Exercising regularly
		Protective health behaviours
<i>Family members' perspectives</i>	<b>Restrictions in family's social life</b>	Reduction of contacts with other family members
		Restriction to home due to the patient dependence on oxygen therapy
	<b>Emotional distress related to COPD exacerbations</b>	Concerns related to the worsening of patients' symptoms
		Fear that patient has a painful death associated to asphyxia
	<b>Tension in couple relationship</b>	Spouses blamed the patient for the COPD diagnosis
		Patients' attitudes and negative emotional reactions
	<b>Financial strain of COPD</b>	Limited patients' ability to work
		Expensive medications with no support from social and health services
	<b>Coping resources</b>	Positive reappraisal
		Getting help and support from family, friends and professional networks
673		Seeking for relevant information about COPD
		Reorganising family routines